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EDITORIAL

What values do the public want their health care systems to use in evaluating technologies?

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For most economists working in the field of health care, particularly those working on the economic evaluation of health technologies, the logic of being concerned about the relative effectiveness of competing interventions and the opportunity cost of the resources involved is instinctive. Difficult choices have to be made within the inevitably limited resources available to publicly funded (and indeed private insurance-based) health care provision. It is an easy step then to suggest one should maximise the utility of a population within the constraints of a predetermined budget or at politically acceptable future cost. For many economists, though not all, it requires only two small steps to move from utility maximisation, to health maximisation and then to operationalise that as QALY maximisation. And, some key reimbursement and/or coverage authorities have bought into that argument as a logical, operational definition of their mandate.

Economists, of course, readily concern themselves as to whether the underlying concepts of cost-effectiveness generally, and of QALY maximisation with a budget constraint in particular, are consistent with economists own definitions of logical behaviour as expressed in welfare theory (for example, the paper by Bengt Liljas and the subsequent comments in this Journal) [1–3]. Those who take an extra-welfarist view of the issues may be less concerned about the fit with economic theory and more about the fit with decision-makers explicit or implicit criteria [4].

What is more, there is a widespread assumption that explicitness and transparency are desirable characteristics in the process of making the necessary difficult choices about what can, and should, be afforded (as, for example, in a proposed framework for classifying decision-making systems using technology assessment) [5]. But it is not clear that such explicitness is desired by all. Many politicians, and perhaps the public they represent, often seem to want to avoid clarity and transparency and prefer difficult choices to be fudged.

In the UK, where 'rationing' has been widely accepted as a necessary characteristic of the NHS, the National Institute for Clinical Excellence (NICE) was originally sold to the public as a way of avoiding the use of ineffective interventions and ensuring that '*effective new treatments will be spread promptly and evenly around the country*' [6]. Nevertheless, NICE has led the way in making its decisions on the availability of specific technologies as transparent and explicit as possible and not hiding the fact when it does not recommend an effective medicine because it is not also acceptably cost-effective. But this 'virtue' of transparency and explicitness receives a very mixed reaction in the media. Some commentators have noted recently that '*public understanding and support for the work of NICE as evidenced by the UK's media coverage, with very few exceptions, has been increasing*'. [7] But virtually, every NICE decision that does not recommend the use of a new drug, or limits its recommended use to a subset of the patients within its broader licence, is still strongly criticised in (politically important) parts of the popular daily press. Arguably, one of the political drivers for the proposed move to value-based pricing (VBP) is to avoid the politically difficult headlines when NICE 'says no'. Instead, if

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an acceptable value-based price cannot be agreed with the company, then the responsibility for a drug not being available to the NHS is passed back to the 'unreasonable' pharmaceutical company and the political hope may be that the opprobrium will fall on the company and not on the NHS [8]. However, this may not in practise be how things are perceived. Based on experience to date, even where the same logic applies as when a medicine is viewed by NICE as not being adequately cost-effective at the price the company has chosen, the company is rarely (if ever) seen as the villain of the piece 'demanding' too high a price; rather, the NHS is viewed as failing to find the necessary money for a new drug. So, even in a country where the reality of 'rationing' (or the more generous sounding 'priority setting') has been an accepted part of the NHS, almost from its inception, politicians find saying no is uncomfortable. And, delegating that responsibility to a body such as NICE only partially removes the discomfort.

In the United States, there is obvious public distaste for rationing of any form with vehement public outcry when it appears that limits are placed on access to care. This was never more apparent than with the furore surrounding the US Preventative Services Task Force (USPSTF) revised guidelines for breast cancer screening [9]. Recommendations that routine breast cancer screening should begin at age 50, as opposed to the previous age threshold of 40, were met with claims that this was the start of unacceptable rationing.

Even in circumstances where there are clear budgetary constraints, care is taken so as to avoid claims of rationing. The Centers for Medicare and Medicaid Services (CMS) administer Medicare, the health care insurance for those aged 65 years and over and certain people with disabilities. For new medical technologies CMS must decide whether to provide coverage from its limited budget. In contrast to the situation in the UK, CMS are particularly vague with respect to their decision-making criteria. Medical technologies are covered if they are deemed 'reasonable and necessary' for the diagnosis or treatment of illness or injury [10]. Lack of clarity in the decision-making criteria has led to uncertainty as to the coverage of medical technology and to what extent CMS can influence the efficient allocation of health care resources [11]. Whilst research has shown that coverage of medical technologies within Medicare, determined largely on clinical effectiveness, often appears to be broadly consistent with a criterion of economic efficiency, a number of explicitly covered technologies are estimated to have a cost-effectiveness ratio greatly in excess of what could be considered acceptable threshold values [12].

In many countries in between the two extremes of the UK and the USA, systems struggle to find what they believe is a socially acceptable balance between providing all that is clinically effective and only that which is economically efficient. In France, as was discussed in a recent EJHE editorial, the Haute Autorité de Santé (HAS) has created a commission '*to perform technology assessment on all relevant dimensions to inform the decision maker'* which now formally is required to include, but is no sense limited to, economic efficiency [13].

As a result, politicians in most countries have been unwilling to engage in an open public debate about how such decisions should be made. They prefer to talk about eradicating inefficiency or structural changes, rather than directly addressing the issue of the criteria on which difficult choices should be made, and there have been few examples of formal exercises to consult the public about decision-making. An interesting but isolated example was a public consultation initiative in Israel, in which a random sample of the population was provided with background materials and over a period of 6 months met to discuss policy questions associated with equity and coverage priorities [14]. But despite the participants' willingness to participate in future consultations, the initiative was not continued. Again, NICE has probably gone further than most such institutions in setting up a standing body—their Citizens Council—to try to understand the values that members of the public, with no professional interest in health care, believe should underpin NICE's technology appraisals and other work. These social value judgements are captured in a document of principles [15]. The views that emerge are broadly consistent with a QALY maximisation approach, and they reject an additional 'rule of rescue'. They do state, however, that '*Decisions about whether to recommend interventions should not be based on evidence of their relative costs and benefits alone. NICE must consider other factors when developing its guidance, including the need to distribute health resources in the fairest way within society as a whole'*. But they do not provide much help as to how the efficiency and fairness should be balanced. But valuable as that exercise is, can such a body of 30 people drawn from a large number of self-selected volunteers, meeting twice a year for 3 days at a time, really reflect the diverse views of the public as a whole? And to what extent are the Council's views inevitably refracted through the prism of the organisation of which it is a part?

As long as politicians for the most part evade the reality of the need for stark choices, then, it is not surprising that the public does not spontaneously recognise that need and suggest how they think the choices should be made. Unfortunately, there are few situations, if any, where we can as economists observe the well-informed revealed preferences of members of the public as they choose between a range of competing (publicly funded) health care systems each allocating scarce resources according to different criteria. Were such situations to exist, we might be

able to begin to understand their preferences without explicit exercises. In practice, we have to rely largely on stated preference studies of one sort or another and these are not always easy to interpret and they require replication and validation. What is more, we might reasonably expect that such preferences will not be universal, but will be nationally or locally contextual—a function of the political and social history of the countries concerned—and strongly influenced by the current systems and their perceived strengths and weaknesses.

Given the importance of the issue, it is curious that there appear to have been very few major, systematic attempts to study how the public really would like to see choices made, although over the years there have been many small academic studies generally addressing specific aspects of the broad issue and focussing on specific contexts. This editorial is not the place to attempt a systematic review of all the evidence, although such a review would be valuable. Suffice it here to selectively illustrate the sorts of issues that studies have addressed and the results they have found. A number of studies have shown that the public would not naturally choose the most efficient allocation of resources and aim simply to maximise QALYs gained. For example, a discrete choice experiment study examined public preferences for allocating organs in liver transplantation and showed that the public would sacrifice some level of efficiency to increase equity and to give a chance of receiving an organ to all groups, including those with the poorest expected survival [16]. Other studies have attempted to assess but have struggled to reach firm conclusions as to whether the nature of the disease problem or the characteristics of the recipient would lead the public to differentially 'weight' a QALY gain [17, 18]. Another recent study used a discrete choice experiment approach to get members of the public to choose between technology scenarios to test, amongst other factors, whether severity of the health state was an important independent factor for the public [19]. Methodological issues abound, not least the issue as to whether surveys, and the immediate responses they invoke, accurately represent some underlying views held by the public or whether discussion and deliberation should be used to allow for reflection, to help develop their ideas and to enable them to provide more considered responses [20].

Yet, despite this patchy evidence that suggests public views are complex and nuanced, many decision-makers have clear statements of the relatively simple criteria they wish to use and as pragmatic economists we can simply respond to these. But would it not be useful to those decision-makers, and all the more to the public on whose behalf they act, to make a major effort to understand relevant public preferences regarding the allocation of scarce health resources? Despite the numerous isolated academic studies, a real debate and engagement with the public does not appear to be happening yet. A recent survey looking at the experiences of priority setting in eight countries concluded that despite the fact that all had statements of principles on which to base priorities, there was no evidence that 'priority setting exercises have led to the envisaged ideal of an open and participatory public involvement in decision-making' [21].

Will things change? Perhaps, the storm of the ongoing international financial crisis will bring a ray, if not of sunshine, at least of reality. In Europe, the financial crisis is making hard choices the focus of attention. Politicians are at last learning to say that desired services, including many that have been publicly provided in the past, cannot (or can no longer) be afforded. Pension expectations are being drawn in; spending on many public services is being considerably reduced. Perhaps, this will create an environment where politicians will be bold and honest enough to engage the public in a serious debate about how these difficult choices should be made, particularly in health. It is the public's money that is being spent and their health that is affected; perhaps as health service researchers, we should attempt to help decision-makers understand more fully what the public think and what their preferences are. Then, at least, decision-makers could act with knowledge of public views rather than in ignorance of them.

We are not the first to worry that current economic evaluation may not be consistent with society's health values [22]. Nor probably will we be the last, because a comprehensive research agenda to address these questions would be both huge and complex. Existing experience shows that it is not easy. The questions, both substantive and methodological, are numerous but should not the health economic community begin systematically to build on the examples of the work to date? It is a fascinating and important area with some very significant implications for the relevance of current economic evaluations.

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